Perceptions regarding HIV status disclosure to children born HIV positive living at Epworth Child and Youth Care Centre in Lambton, Ekurhuleni, South Africa

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By

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DECLARATION

I hereby declare that this research report is my own original and unaided work and that I have correctly referenced all the sources utilised. This research report has not been submitted previously for any degree or examination.

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CHAPTER ONE
<u>INTRODUCTION TO THE STUDY</u>

1.1 Introduction

According to Dube (2009), the world is host to 40 million people living with HIV and AIDS with at least 24 million persons already having been lost to the disease. Communities are also raising approximately 15 million children orphaned by HIV and AIDS and taking care of many who are critically ill with the disease. According to UNAIDS (2003), all over the world, the AIDS pandemic has a profound impact and brings out both the best and the worst in people. It triggers the best when individuals and groups come together in solidarity to combat government, community and individual denial and to offer support and care to people living with the virus, including children. It brings out the worst when individuals are stigmatised and ostracized by their loved ones, their families and their communities, and are discriminated against individually and institutionally (UNAIDS, 2003).

Children infected with HIV live in many different circumstances. Some live with their biological parent or parents, others with older sisters and brothers, grandmothers, uncles and aunts (Mbambo, 2004). Some children live with formal and informal foster parents who are not family members, or have been adopted, or are living in a shelter or children's home such as Epworth Youth and Child Care Centre [EYCCC] in Lambton, Germiston in South Africa, which forms the basis of this study. Furthermore, some children live in child-headed households and have to take care of younger siblings, sometimes with little support from others such as neighbours, community members or social workers (Mbambo, 2004). These children, when identified, may also be placed in a children's home as a form of alternative care, in order to have their physical, cognitive, emotional and social needs attended to.

1.2 Statement of the problem and rationale for the study

The advent of the Anti-Retroviral Therapy (ART) and the availability and accessibility of ARVs has resulted in prolonged life spans for people living with HIV. This includes children born with the virus. The introduction of the ART programme in South Africa and the massive roll-out of ARVs is a welcome development for most infected and affected persons as it enhances their immune system (Van Dyk, 2008). However, there seems to be underlying complications concerning disclosure and non-disclosure of HIV status to children who are

born HIV positive living in Child and Youth Care Centres. Such non-disclosure therefore results in children having to take medication twice on a daily basis without knowledge and / or understanding of the reason why they are taking the medication. Social service staff at Epworth seems to be concerned about the issue of disclosure and non-disclosure, and various strategies have been attempted to find a way to deal with the issue (Interview with key informant, 07/01/2012). However, there is no clear strategy or policy with regard to disclosure and non-disclosure of HIV status to children born HIV positive living at Epworth. In such institutional settings, it would be anticipated that social service workers, including social workers, social auxiliary workers, educational psychologists and child care workers, together with support staff who render various services to these children would see the need to disclose the HIV status in order to help the children with adherence to medication and to deal with their positive HIV status.

While there is extensive literature on HIV status disclosure to children (Mtshizana, 2004; Naeem-Shaik & Gray, 2005; Pantell, 2006) there would seem to be a paucity of research focusing on perceptions regarding the effects of HIV status disclosure or non-disclosure to children born HIV positive living in institutions and / or in alternative care placements. The need therefore exists to explore the perceptions of social service workers around the effects of disclosure and non-disclosure of children's positive HIV status, specifically children born HIV positive living in institutions of alternative care. Specifically, the Epworth Child and Youth Care Centre in Lambton, Germiston, Ekurhuleni, east of Johannesburg in South Africa serves as a useful context for the study.

It was anticipated that the findings of this study would contribute to raising awareness among social service workers regarding the effects of disclosure and non-disclosure of HIV status to children born with the virus. This would facilitate the enhancement of intervention strategies, thereby advancing knowledge and practice within the discipline of social work. It was anticipated that the study might be of value to the government as it plans to embark on a voluntary HIV testing of children in primary schools, through the provision of information and necessary procedures to be considered when dealing with the issue of disclosure and non-disclosure of the HIV status to children.

1.3.1 Brief background of Epworth Child and Youth Care Centre

Epworth Youth and Child Care Centre in Lambton, Germiston, South Africa, was established as an orphanage 1913. It currently serves to care for children who are found to be in need of care according to Section 156 of the Children's Act No 38 of 2005, as amended. Founded by the Methodist Church of Southern Africa, Epworth Child and Youth Care Centre's vision is to encourage hope in the children and families whom it is entrusted with, to inspiring a passion which colours the work that it undertakes, to make dreams come true and teach its children to dream and have purpose in life (Epworth annual report, 2010). Epworth has responded to many new challenges over the years and more recently, to the challenge of caring for children and their families during the era of the deadly HIV/AIDS. Thus, the vision of the organisation is to be an evolving resource and treatment hub for children, families and members of the community that it serves (Epworth annual report, 2010). It presents itself as a safe residential haven and training ground for many children and a gateway between brokenness and healing. It is the belief of the organisation that every child has a purpose and meaning in life, and that children have a right to be loved, cared for and defended from harm. The organisation has various programmes for its children, and these include, but not limiting to the following:

1.3.2 Residential care programme

Every year, up to 90 children aged between 4 and 18years are cared for at Epworth's residential care programme. Children in the residential care programme are children referred by courts, due to abandonment, neglect and abuse and some have chronic illnesses such as HIV/AIDS, some children have substance abuse problems, while some have intellectual and / or physical disabilities (Epworth annual report, 2010). The residential programme aims at providing short-term care to children in need, who have been placed at the Centre by courts. There is a strong emphasis on therapeutic interventions aimed at restoring individual and family functioning, with an aim of reuniting children with their families within a period of two years and / or to place them in foster care within the same period (Epworth annual report, 2010).

1.3.3 Assessments and therapy programme

Through the therapeutic treatment centre, assessments, therapy and family preservation services are provided to children in residential care together with their families and / or care givers. These services are provided by a team of educational and counselling psychologists together with occupational therapists (Epworth annual report, 2010).

1.3.4 Family reunification Programme

Family preservation and reunification is the main of this programme, and it provides a care and treatment plan for both the child and his or her family or significant others. Reunification can take time depending on the nature and the extent of the case being dealt with (Epworth annual report, 2010).

1.3.5 The independent living programme

This programme provides long-term care to children who cannot be reunited with their families or placed within the extended family network or foster care. It focuses on providing children with life skills, education and training in preparation for independent living. The programme supports young people until their 18th birthday year, however, they may stay longer if need be (Epworth annual report, 2010).

1.3.6 Residential treatment programme

The aim of this programme is to provide short-term crisis intervention to families in crisis, and the entire family occupies the house together with the child at risk and therapeutic interventions will be offered in order to keep the family together. The process takes about six months to one year and its success lies in the early identification of a crisis and immediate intervention (Epworth annual report, 2010).

1.3.7 Early learning development programme

This programme pays special attention to children in Epworth's residential care who are developmentally delayed, either due to their HIV status or past experienced trauma. The therapy team develops a programme for each child, aimed at assisting him or her to reach his or her developmental milestones, in order to reduce risks of a disability and / or poor

performance at school. In this programme, therapists work hand in glove with school teachers so that they, teachers, can reinforce the programme developed for the child in the classroom (Epworth annual report, 2010).

However, even though Epworth Child and Youth Care Centre have different programmes that are earmarked at helping the children in different ways, it is faced by the dilemma of HIV status disclosure to children born HIV positive living in its residential care programme.

1.4.1 Definition of terms

1.4.2 Child / Children

According to the Children's Act No 38 of 2005, as amended in 2008, a child means a person under the age of 18 years. This means that 18 years is the age at which the law recognises the right of a young person to act as an adult. However, there are instances where children below this age should be and are legally allowed to make decisions on their own without the assistance of an adult. For example legal abortions and consent to the provision of HIV testing and medical treatment of young children can be done by a child of 12 years and above according to the new Children's Act No 38 of 2005, as amended in 2008.

1.4.3 HIV and AIDS

According to the World Health Organization (WHO), HIV is the acronym for Human Immunodeficiency Virus. WHO further explains that HIV is 'human' because this immune deficiency virus has been discovered to cause disease in people, and it weakens human being's immune system, which normally protects persons from diseases and / or infections, and like all viruses it attacks the body by replicating itself using the body's cells (UNAIDS, 2003). This virus destroys the blood cells that are crucial for the body's defence against illness. It is this virus that is responsible for causing the syndrome known as AIDS, which according to WHO is the acronym for Acquired Immune Deficiency Syndrome in which the body's immune system breaks down and is unable to fight off certain infections, known as "opportunistic infections" and other illnesses that take advantage of a weakened immune system (UNAIDS, 2003). A person can be HIV positive and not have AIDS. After a diagnosis of HIV, persons may develop AIDS if they are not treated with anti-retroviral therapy and their CD4 cell count drops below 200 (UNAIDS, 2003). The CD4 cell count is a

measure of the number of disease-fighting cells in the body and indicative of the extent of the infection with the HI Virus (UNAIDS, 2003) .

1.4.4 Child-headed households

According to Meintjes, Hall, Marera and Boulle, (2009), define child-headed households as households where all members are under18 years of age. An analysis of the 2006 General Household Survey found 0.67% of children living in child-headed households. This is equivalent to roughly 122 000 children out of 18.2 million children in South Africa (Meintjes et al., 2009).

1.4.5 Stigma

In his seminal publication, Goffman (1963, p. 13) described stigma as "an attribute that is deeply discrediting", and is defined by society on the basis of what society regards as being different or deviant. Stigma is also said to be a mark branded on the skin and is cast as a socially constructed deviant label (Green, 2009).

1.4.6 Residential / Institutional care

In South Africa, institutional care is defined as a facility for the provision of residential care to more than six children outside the child's family environment in accordance with a residential care programme(s) suited to children in the facility (Children's Act 38, 2005, amended in 2008).

1.4.7 Social service workers

According to the Children's Act 38, 2005, amended in 2008, a social service worker is anyone who cares for the child, and includes probation officer, development worker, child and youth care worker, and a registered social auxiliary worker and social security worker. However, for the purpose of this study a social service worker refers to all employees of Epworth Child and Youth Care Centre, including therapists (Psychologists, Social Workers and Occupational Therapists), childcare workers and support staff.

1.5 Scope of the study

The geographical location of the study was limited to Epworth Child and Youth Care Centre in Lambton, Germiston, South Africa. Epworth is one of the alternative care institutions that cater for children found in need of care in terms of Section 156 of the Children's Act 38 of 2005, as amended in 2008. Epworth also presents itself as a preferred setting for the study as it has the required sample for the study, and also cares for children who were born HIV positive and not knowing their HIV positive status.

1.6 Overview of the research design and methodology

The study employed a qualitative research design that was exploratory and descriptive in nature. The criteria for inclusion of research participants were social service workers working for Epworth Child and Youth Care Centre in Lambton, Germiston, South Africa. Stratified purposive sampling was used to recruit 15 participants from Epworth to gather data for the study. These participants were drawn from three employee categories, namely therapists, child care and support staff. Specifically, these participants held positions of educational psychologists, occupational therapists, child care workers, social auxiliary workers and support staff. An interview was also conducted with a significant stake holder. The research tool was an interview schedule administered through face-to-face semi-structured individual interviews. Responses were analysed using thematic content analysis.

1.7 Limitations of the study

The limitations inherent in the study included the following:

- The small, stratified sample precluded generalisation of findings to the broader population of social service professionals concerning the perceived effects of disclosure and non-disclosure of HIV status to children born HIV positive living in residential or alternative care placements similar to Epworth Child and Youth Care Centre. However, since the study was qualitative and exploratory in nature, generalisation of the findings was not intended.

- As participants for the study were recruited through a stratified sample, finding willing participants was a challenge, especially in the category of therapists due to

their busy schedules. However, the researcher was flexible, and suitable times were arranged which were convenient to the participants' work schedules.

- Some participants may have furnished socially desirable responses; despite being assured of confidentiality and that there were no correct or incorrect answers.

- All the participants who participated in the study did not agree to audio tape recording, which might have led to loss of very important data as the researcher could not write down everything that they said.

- A further limitation related to the fact that in the qualitative data analysis, some themes were articulated by only one or two participants. However, reflection on such themes is important as this would contribute to the overall understanding and interpretations made in the study.

1.8. Organisation of the report

Chapter One provided an overview and orientation to the study. Chapter Two of the research report focuses on the literature review and also examines theory and research relating to perceived effects of HIV status disclosure and nondisclosure to children born HIV positive living in institutional care centres, thereby providing a theoretical framework for the project. The research design and methodology are described in Chapter Three of the report, while Chapter Four presents the analysis and discussion of data collected during the study. Chapter Five, which is the last section of the research report, describes the main findings, conclusions and recommendations that emerged for community awareness, policy changes and future research.

<center>**CHAPTER TWO**</center>

<center>**REVIEW OF THE LITERATURE AND THEORETICAL FRAMEWORK**</center>

2.1 Introduction

According to the United Nations Research Institute for Social Development (UNRISD) (2003), the scale of the HIV and AIDS pandemic has exceeded all expectations since its identification 20 years ago. Most transmission of HIV to children is from mother to child during pregnancy, childbirth or through breastfeeding or wet nursing. It is important to identify children who are HIV positive at an early age so that they and their families can have optimal support and care (Shisana, Peltzer, Zungu-Dirwayi & Louw, 2005. This chapter provides the literature review and theoretical background to the study. The main issues that are discussed in this chapter are the HIV/AIDS pandemic in general, children and HIV/AIDS, legal and ethical aspects related to HIV/AIDS in South Africa, managing HIV disclosures to children, HIV related stigma and discrimination and child and youth care centres in South Africa.

2.2 HIV/AIDS pandemic

Sub-Saharan Africa continues to bear the brunt of the global epidemic with almost 25million HIV infected individuals (Van Dyk, 2008). South Africa also continues to be the 'world's capital' of HIV/AIDS, with approximately one thousand people dying of an AIDS related illness every day and a further one thousand being newly infected with HIV per day (Venter, 2008). Venter (2008) argues that South Africa has the world's highest HIV prevalence rate compared with other countries and it is estimated that there are 5.6 million South Africans living with HIV out of a population of about forty-six million. Squire (2007), however highlights the fact that people with HIV/AIDS can have more pressing issues that take precedence in their lives than the virus itself, for example struggles against poverty, unemployment, education and other health problems. Nevertheless the virus is a constant part of their lives because it presents specific medical and social problems, which may include discrimination, rejection and stigmatization. In contexts of high HIV prevalence such as South Africa, HIV/AIDS becomes everyone's problem and people are most likely to be living with HIV within families and neighbourhoods of people who are also affected (Squire, 2007). Furthermore, those who are HIV negative or who do not know their status, have their lives

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shaped by concerns of HIV transmission and illness and in these circumstances, the resilient and creative efforts of people living with HIV/AIDS need to be recognized and learned from, whether they foreground HIV or, at times, give precedence to other concerns (Squire, 2007).

Mashau (2008) describes how those infected and affected undergo enormous pain and suffering. Furthermore, Mashau (2008) argues that whenever and wherever HIV/AIDS strikes, the consequences are devastating and unbearable, as the pandemic, in certain instances, reveals tragic consequences of personal actions that may directly harm others, and of negligence that might expose persons to additional risk. Parker and Aggleton (2003) distinguished between three phases of the AIDS epidemic in any community. The first is the epidemic of HIV infection, an epidemic that typically enters every community silently and unnoticed and often develops over many years without being widely perceived or understood. The second phase is the AIDS epidemic itself, which is the syndrome of infectious diseases that can occur because of HIV infection, but typically after a delay of a number of years. The third epidemic, potentially the most explosive, is the epidemic of social, cultural, economic and political responses to AIDS. According to Parker and Aggleton (2003), the third phase is characterized by exceptionally high levels of stigma, discrimination and collective denial that are as central to the global AIDS challenge as the disease itself.

2.3 HIV/AIDS among children and status disclosure

The Department of Health (2008) point out that in South Africa women bear the brunt of the epidemic of HIV and AIDS, as they account for 55% of people living with HIV and AIDS. This phenomenon is more pronounced in the age groups 20-24 years and 25-29 years where the HIV prevalence rate is 23.9% for women compared to 6.0% for men and 33.3% for women compared to 12.1% for men respectively (Johnson, 2009). Of the estimated 5.6 million of the infected people in South Africa, 294 000 were children aged 0-14 years (Statistics South Africa, 2009). These estimates are consistent with those of the Department of Health and UNAIDS for 2008 which state that of the 5.5 million people living with HIV or AIDS, 235 000 are children. Whilst HIV is spread predominantly through unprotected sexual intercourse, other modes of transmission remain important and these include Mother to Child HIV Transmission (MTCT), blood transfusion, exposure to blood and intravenous drug use (IDU). According to Heyns and Swanevelder (2005) HIV is transmitted to approximately one

third of babies of HIV positive mothers if there is no medical intervention, such as the use of antiretroviral drugs, obstetric practices including caesarean delivery and safe infant feeding practices.

According to Children's Institute (2010), a significant number of children in South Africa are living with HIV and AIDS. The survey further indicated that 129 621 children aged 2-4 years and 214 102 children aged 5-9 years were living with HIV or AIDS in 2008. HIV has also been identified as the major contributor to an increase of 42% of South Africa's 2008 under-five year mortality. It is further argued that children do not have sufficient access to AIDS treatment and care because available services are mostly designed for adults (Johnson, 2009). Serious challenges around the skills of health workers and capacity to manage and treat children with AIDS including lack of appropriate ART formulations also remain (Shisana et al, 2005).

Although there are an estimated 1.6 million children living with HIV/AIDS in sub-Saharan Africa, issues of disclosure of HIV status to infected children has received relatively less attention in resource-limited settings (Myer, Moodley, Hendricks & Cotton, 2006). Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuza, Mermin, Malamba & Bunnell (2006), highlight two types of disclosure, complete parental disclosure and partial disclosure. Complete parental disclosure refers to a situation in which "both the caregiver and child concur that the primary caregiver has told the child about his or her HIV disease and drugs, which prevent opportunistic infections and help prolong life" (Bikaako-Kajura et al, 2006, p. 88). Partial disclosure refers to a situation in which the child is not fully aware of his or her HIV disease but is suspicious, asks questions of the caregiver about the disease and the drug, and, in many cases, assumes that the drug is a cure (Bikaako-Kajura et al, 2006, p. 89). However, with the growing access to antiretroviral therapy (ART) in many African countries, South Africa included, HIV infected children survive to older ages, and in turn discussing HIV status with infected children is most likely to become an important issue in paediatric HIV care (Myer et al, 2006).

Pantell (2006) argues that as children born with HIV mature into adolescence their families inevitably face the issue of disclosing their diagnosis to them. However, the question of how and when to disclose to a child born with HIV, may be the source of much debate between

those who care for him or her (Pantell, 2006). Although published guidelines encourage disclosure to school-aged children, parents and guardians may have reservations for reasons such as concern over the child's reaction, fear of child telling others, or guilt about transmitting the virus to a child (Pantell, 2006). Naeem-Shaik and Gray (2005) highlight that disclosure of a child's HIV status is one of the most sensitive issues to caregivers. It is particularly difficult for caregivers who are themselves HIV positive, especially where the child's HIV positive status is a result of mother-to-child transmission (Naeem-Shaik and Gray, 2005).

2.4 Legal and ethical aspects

Children with HIV/AIDS and their caregivers are affected by a range of laws. Caregivers include parents and legally appointed guardians, as well as unofficial caregivers who care for children who have no parents or guardians. These laws relate to who may consent to HIV testing and medical treatment, including access to ART, access to government grants and protection from discrimination. The Children's Act (No. 38 of 2005, as amended), regulates HIV testing and provision of medical care to children. Section 133(1) of the Children's Act, (No. 38 of 2005, as amended), states that "no person may disclose the fact that a child is HIV-positive without consent given in terms of subsection (2)", except in exceptional circumstances that will be also in the best interest of the child. Furthermore, Naeem-Shaik and Gray (2005, p. 23) highlighted that "an adult has the right to keep personal medical information private", this right to confidentiality and privacy extends to a child as well, as the Constitution of South Africa gives everyone, including children, the right to privacy. No person may disclose the HIV status of the child without consent either from the child, or a person who has the right to consent on behalf of the child (Naeem-Shaik & Gray, 2005).

From a legal and rights perspective, children have the right to participate in decision making about their own health care and knowledge of their status may also help to promote adherence to treatment (Naeem-Shaik and Gray, 2005). Furthermore, a 12 year old child can legally terminate pregnancy without consulting an adult person. According to the South African Council for Social Service Professions, (SACSSP), (2007, p. 49), "HIV infection and AIDS are one of the most challenging matters that the law making authorities have to deal with in South Africa". This is due to the fact that this pandemic affects individuals, groups

and communities in their totality. The effect of HIV and AIDS is broad and relates to the health, social and psychological well-being of those infected as well as their significant others and the communities in which they live (SACSSP, 2007). In terms of legislation, the Social Service Professions Act, No 110, of 1978 does not provide for information on the disclosure or nondisclosure of HIV status. However, the rules relating to unprofessional conduct are clear on how social service professionals should treat confidentiality with their clients. It is further emphasised that the client's right to confidentiality regarding his or her HIV status should be maintained (SACSSP, 2007). According to the Children's Institute (2010), children have the right to services which enable families and parents to care and protect them. It further emphasizes that such interventions need to happen early when problems can still be prevented to ensure that children remain in a protective family environment.

2.5 Managing HIV disclosures to children

According to Mbambo (2004, p. 4), disclosure should be seen as "a process of telling a child that they have HIV disease and helping the child to understand what this means". Through the process, the child should come to know about the diagnosis, the infection and disease process, together with health changes that could occur (Hamilton, 2006). Again the child should know strategies to prolong a healthy life, including adherence to ART, risk factors, responsibilities now and in the future, together with how to cope with possible negative reactions of others (Hamilton, 2006). Conversely, non-disclosure refers to "a situation where the child is unaware of his or her infection" (Bikaako-Kajura et al., 2006, p. 88).

According to Myer et al. (2006), despite the emerging views around the importance of discussing HIV with infected children, there are some insights around the challenges associated with disclosure, resulting in many caregivers and healthcare providers not telling children about their HIV status. Not knowing or having a confused understanding about HIV/AIDS may cause difficulties with adherence. Keeping HIV – positive children ignorant of their status may also add to the psychosocial challenges that they face, such as experiencing stigma and issues around sexuality (Naeem-Shaik and Gray, 2005).

2.6 HIV related stigma

Stigma poses several challenges. Stigma and discrimination are part of complex systems of beliefs about illness and disease that are often grounded in social inequalities (Goffman, 1963). Exclusive use of the stigma framework has frequently served as a means of giving short shrift to powerful social inequalities that are much harder to identify and conceptualize. Goffman (1963) developed what has become the benchmark social theory of the association between stigma and disease. Fourie (in press), highlights the problem of alienation related to the experience of stigma and explores this phenomenon within the sphere of communication disorders, where it is said that an individual experiences a loss of identity, perhaps even not knowing who he or she is anymore. The person becomes demoralised, lost and depressed due to such alienation and rejection.

In all cases of disclosure of children's HIV status, it is essential that the process takes into account family needs, wishes, and opinions, as well as community norms and pressure (Naeem-Shaik and Gray, 2005). It is further argued that caregivers should as far as possible, feel a sense of control over how disclosure happens. Professionals, both social and health care, should explore the implications of disclosure and non-disclosure with concerned children and help them plan for disclosure with the aim of promoting adherence and normalisation of HIV infection (Mtshizana, 2004).

Ross and Deverell (2010), also highlight the issue of dual stigma in the context of TB and HIV or AIDS, where it is argued that if someone is diagnosed with TB, the assumption is that this person is also HIV positive due to the dualisation of these two distinct diseases. Scambler (2009) argued that stigma puts a mark of disgrace or reproach on an individual and society still discriminates and stigmatises people due to HIV/AIDS. Parker and Aggleton (2003) also state that much of what has been written about stigma and discrimination in the context of HIV and AIDS has emphasized the complexity of these phenomena and has attributed people's inability to respond to them more effectively to both their complex nature and their high degree of diversity in different cultural settings.

2.7 HIV related discrimination

According to UNAIDS (2003), discrimination follows stigma and involves the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Discrimination, together with stigma can breach fundamental human rights and can occur at a number of different levels including: political, economic, social, psychological and institutional levels. HIV-related stigma and discrimination build upon and reinforce existing prejudices, and also play into and strengthen existing social inequalities – especially those of gender, sexuality and race (UNAIDS, 2003). Discrimination plays a key role in producing and reproducing relations of power and control, as it causes some groups to be devalued and others to feel that they are superior (UNAIDS, 2003). Again, prejudicial and stigmatising thoughts frequently lead a person to do or not do something that denies services or entitlements to another person. For example, they may prevent health services being used by persons living with HIV and AIDS or terminate their employment on the grounds of their HIV status (UNAIDS, 2003).

Discrimination occurs when a distinction is made against people that results in their being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong to a particular group (UNAIDS, 2003). The human rights framework provides access to existing procedural, institutional and other monitoring mechanisms for enforcing the rights of people living with HIV and AIDS, including children, and for countering and redressing discriminatory action. According to UNAIDS (2003), appropriate reporting and enforcement mechanisms ranging from legal aid services to hotlines for reporting acts of discrimination and violence can provide powerful and rapid means of mitigating the worst affects of HIV and AIDS-related discrimination across all population age groups.

Moreover, discrimination can lead to depression, lack of self-worth and despair for people living with HIV and AIDS even though they are not the only ones at risk from this fear and prejudice (UNAIDS, 2003). Ensuring that people living with HIV and AIDS also contribute to society can be an effective way of breaking the cycle of stigma and discrimination. In order to win the fight against discrimination experienced by those infected and affected by the HIV virus, there is a need to confront stigma and discrimination so that fear, shame, ignorance, labelling and injustice can be eradicated.

UNAIDS (2003) maintains that HIV and AIDS continue to ravage, mainly, the adult population of sub-Saharan Africa leading to many children becoming orphans with little or no prospects of a real future. This scenario also leads to children, after the death of their parents, being shunted among relatives and extended families and finally being institutionalised for various reasons (Lumbi, 2007). Furthermore, HIV and AIDS still continue to carry a stigma in many parts of Africa and are still associated with shame, fear and rejection (UNAIDS, 2003). When children are institutionalised, they also may experience stigma and discrimination in their daily encounters and so the stigma and discrimination associated struggles are further psychological effects that children born HIV positive have to endure, apart from being institutionalised (Lumbi, 2007).

2.8 Early childhood development

Any considerations of disclosure or non-disclosure among children will need to take into account the stage of development of the child. Each stage of development will have an impact on the level of cognitive and emotional readiness of the child and will have an impact on how the child deals with and reacts to such disclosure (or non-disclosure which may be accompanied by confusion and suspicion). Berk (2003) maintains that, human development may be divided into three broad domains or aspects. The first aspect is described as physical development, which includes changes in body size, proportions, appearance, and the functioning of various body systems, for example, brain development, perceptual and motor capacities and physical health (Berk, 2003). The second domain is cognitive development, which refers to "development of a wide variety of thought processes and intellectual abilities, including attention, memory, academic and everyday knowledge, problem solving, imagination, creativity, and the uniquely human capacity to represent the world through language" (Berk, 2003, p. 5). Emotional and social development is the final aspect of human development and it entails the development of "emotional communication, self-understanding, ability to manage feelings, knowledge about other people, interpersonal skills, friendships, intimate relationships, and moral reasoning and behaviour" (Berk, 2003, p. 5).

It is difficult to theoretically divide the flow of time into distinct phases. Child development is usually segmented into five periods, with each period bringing with it new capacities and social expectations (Slater & Bremner, 2005). According to Berk (2003), the first stage of

child development is the *prenatal period*, and it begins from conception to birth. This period is the most rapid phase of change, during which a one-celled organism is transformed into a human baby with remarkable capacities for adjusting to life in the surrounding world. *Infancy and toddlerhood, which starts from birth to 2 years,* is the second stage of child development. During this stage, dramatic changes in the body and brain support the emergency of motor, perceptual, and intellectual capacities such as language and first intimate ties to others (Berk, 2003). Usually, infancy spans the first year and toddlerhood spans the second, during which children take their first independent steps, marking a shift to greater autonomy (Slater & Bremner, 2005).

The third phase is *early childhood* and it starts from 2 to 6 years. During this stage the body becomes longer and leaner, motor skills become refined, and children become more self-controlled and self-sufficient (Berk, 2003). Play is important during this stage and supports all aspects of psychological development. This is also the phase where thought and language expand significantly and a sense of morality becomes evident and children begin to establish ties with peers (Berk, 2003). Following the third phase is *middle childhood,* which starts from 6 to 11 years. At this stage, children learn about the wider world and master new responsibilities that increasingly resemble those they will perform as adults (Slater & Bremner, 2005). Moreover, during middle childhood phase, children display more logical thought processes, mastery of basic literacy skills, and advances in self-understanding, morality and friendship (Berk, 2003).

The final and fifth stage is the *adolescent* stage, which is the bridge between childhood and adulthood, and it begins from 11 to 20 years (Berk, 2003). During this stage, puberty leads to an adult-size body and sexual maturity. Furthermore, thoughts become abstract and idealistic and school achievement becomes more serious as young people prepare for the world of work. The major concerns of the stage include defining personal values and goals and establishing autonomy from the family (Berk, 2003). Each of the above stages thus imply different levels of cognitive and socio-emotional competences, needs and challenges for the child concerned. These would need to be taken into account in considerations around disclosure or non-disclosure of HIV/AIDS status to the child concerned.

2.9 Child and youth care centres

In South Africa, a child and youth care centre is a facility that provides residential care to more than six children outside of the child's family environment according to a residential programme suitable for children in the facility (Mahery, Jamieson & Scott, 2011). Due to the devastating effects of HIV/AIDS in South Africa, there are a number of both governmental and non-governmental organisations that provide shelter to both the infected and affected persons of South Africa, including children. De Vos (1997) highlights that places like children's homes, also known as Child and Youth Care Centres (CYCC) were historically established for orphaned, needy and child victims of epidemic outbreaks, however, presently children requiring alternative care also come from dysfunctional families and may require emotional support, which is not always available in residential care. In residential care, children depend on their peers throughout their development, but would need consultation and support from significant adult caregivers to make the right choices in life. Perumal and Kasiram (2009) conducted a study of children living in foster care and in children's homes and their findings showed that there are both positive and negative issues around staying in these two safety facilities. A lack of trained staff, negative peer influence and survival of the fittest are some of the highlighted concerns of living in children's homes.

However, another assumption was that although both foster families and children's homes may be inadequately equipped to deal with challenges of children in need of care, children's homes may be better resourced by the State than foster families to cope with vulnerable children, therefore challenging the dominant view of families always providing the best environment for caring for vulnerable children (Perumal and Kasiram, 2009). Hochfeld (2007) argues that many families are unable to uphold their inherent ability to care effectively as they are ravaged by HIV/AIDS, poverty and violence. According to Altshuler and Poertner (2002) youths living in institutional care take more risks and have more threats to achievement and have poorer peer influences. In addition, youths usually do well in terms of resilience and problem-solving skills, and feelings of safety. Hobbs, Hobbs and Wynne (2007) also argued that children in residential care tend to develop long-standing emotional, behavioural and learning difficulties, due to a distinct weak human resource component that exists in residential care.

2.10 Related studies in South Africa and other Sub-Saharan countries

Myer, Moodley, Hendricks and Cotton (2006) conducted a study on the perspectives of health care providers on discussing HIV status with infected children. The study was conducted at a primary care paediatrics HIV clinic based at a large tertiary hospital in Cape Town, South Africa. Overall, 40 healthcare providers were interviewed. Of those interviewed, 20 said that they had talked with a caregiver about discussing HIV with an infected child in the past and, 7 said they had been involved in disclosing a child's HIV status to the child (Myer et al., 2006). The study further found that most providers believed that the optimal age for discussing a child's health should happen at age 6, with the most common reason for this age being the emerging ability of a child to understand the concept of health and disease, and / or when they start formal schooling and interacting with other peers (Myer et al., 2006).

However, concerning HIV status disclosure discussions with children, the study found that participants gave the age 10, or before the onset of puberty, as the best time to have specific discussions about HIV/AIDS with infected children, usually because age 10 would be the approximate age at which children will be able to understand more complex concepts of chronic illness (Myer et al., 2006). It terms of who should lead the discussions on disclosure of the child's positive HIV status, the study indicated that participants felt that caregivers should take the initiative and lead the discussions. However, these caregivers will need support on disclosure discussions from a healthcare worker, for example, from counsellors, doctors and nurses as they play an important role in providing appropriate biomedical information to caregivers and infected children (Myer et al., 2006).

Furthermore, Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuza, Mermin, Malamba and Bunnell (2006), conducted another similar study in Uganda, where the study explored disclosure of HIV status and adherence to daily drug regimens among HIV-infected children at the Mildmay Centre in Uganda. It emerged in the study those children who experienced complete parental disclosure of their positive HIV status, had good adherence to medication and were able to overcome external adherence challenges. However, on the other hand, the study revealed that partial or non-disclosure strained both the child and the caregiver, since

the caregiver needed to apply a combination of force and persuasion to get the child to adhere (Bikaako-Kajura et al., 2006).

2.11 Role of care-givers and social service workers

A care-giver is anyone who cares for the child, and includes: grannies, aunts, and other relatives who care for the child with the consent of the parents or the guardian of the child (Mahery, Jamieson & Scott, 2011). The term care-giver also refers to a foster parent, someone who cares for the child whilst the child is in a temporary safe care, the head of a shelter where the child receives services, the head of a child and youth care centre where the child was placed, or a child and youth care worker supporting children in the community without care in the family and it can be a child (16 years and older) heading a child headed household (Mahery et al., 2011). The role of care-givers or social service workers is to assist in the provision of quality care for children and support for families providing for the welfare and best interests of the client. In addition, care-givers also contribute to the development and the implementation of the child care programmes within an alternative care placement (Mahery et al., 2011).

Furthermore, social service workers or care-givers positively interact with the children nurturing their confidence and self-esteem, and giving each child individual attention and comfort as required (Franklin, 1996). In collaboration with other stakeholders, social service professions or care-givers, assist in planning for the on-going development of the child and participate in supervising indoor and outdoor environments to provide safety for the child at all times. Providing therapeutic services and interventions and protecting children from potential physical, emotional, sexual, psychological, or any form of abuse, are some of the roles that social service professionals play (Mahery et al., 2011). It is also the duty of a social service worker to empower, advocate, educate and motivate children to become positive contributors in society in future.

2.12 Chapter Summary

This chapter provided a theoretical framework for the study by focussing on issues around children and HIV and AIDS, HIV/AIDS among children and status disclosure, legal and ethical aspects, managing HIV disclosure to children, HIV related stigma and discrimination,

early childhood development, child and youth care centres in South Africa, related studies in South Africa and other Sub-Saharan countries and the role of care-givers and social service workers. These were viewed through the lens of the perceived effects of disclosure and non-disclosure of HIV status to children born HIV positive living at Epworth child and youth care centres. Against this backdrop, the methodology underpinning the study is discussed in the following chapter.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

The chapter provides an explication of the steps followed during the research process. It also provides the research questions and the aim and objectives of the study. It describes the approach, the research design and its sampling procedures, research tools that were employed, the data collection methods and the analysis together. Ethical issues that were considered are also explained.

3.2 Research questions

The study was guided by the following questions:

- What are the perceptions of social service workers regarding the effects of HIV status disclosure to children living in a Child and Youth Care Centre?

- What do social service workers perceive as the general effects of HIV status non-disclosure to children living at a Child and Youth Care Centre?

- What are some of the experiences that these social service workers have encountered concerning disclosure and non-disclosure of the children's HIV status?

- What role, if any, do social service workers play regarding children's HIV status when conducting their therapeutic interventions to these children?

- What do social service workers recommend concerning disclosure and non-disclosure of children's HIV status?

3.3 RESEARCH AIM AND OBJECTIVES

3.3.1 Primary aim

The primary aim of the study was to explore the perceptions of social service workers about the effects of HIV status disclosure and non-disclosure to children born HIV

positive living at Epworth Child and Youth Care Centre in Lambton, Ekurhuleni, South Africa.

3.3.2 Secondary objectives

The secondary objectives of the study were:

- To explore the perceptions of social service workers regarding the effects of HIV status disclosure to children living at Epworth Child and Youth Care Centre in Lambton, Ekurhuleni South Africa

- To elicit social service workers' perceptions regarding the general effects of HIV status non-disclosure to children living at Epworth Child and Youth Care Centre in Lambton, Ekurhuleni South Africa

- To determine social service workers' experiences concerning disclosure and non-disclosure of the children's HIV status at Epworth Child and Youth Care Centre in Lambton, Ekurhuleni, South Africa

- To investigate the role, if any, played by social service workers regarding children's HIV status when conducting their therapeutic interventions with HIV positive children living at Epworth Child and Youth Care Centre in Lambton, Ekurhuleni, South Africa

- To ascertain social service workers' recommendations concerning disclosure and non-disclosure of children's HIV status, residing at Epworth Child and Youth Care Centre in Lambton, Ekurhuleni, South Africa

3.4 METHODOLOGY

3.4.1 Research Strategy

The study took the form of an exploratory-descriptive research design located within a qualitative paradigm. Exploratory research is conducted in order to gain insight into an unexplored situation, individual or phenomenon so as to develop a hypothesis or to formulate a problem (Legard, Keegan and Ward, 2003). The study was exploratory because it aimed at exploring the perceived effects of HIV status disclosure and non-disclosure to children born

HIV positive living at Epworth. Descriptive research refers to a more intensive examination of phenomena and their deeper meanings that will lead to a thicker description. In this case, the research strived to provide a deep description of the perceived effects of disclosure and non-disclosure of HIV status to children living at Epworth by further examining the experiences, roles and recommendations that social service workers ascertain regarding children and HIV status disclosure or non-disclosure.

Legard, Keegan and Ward (2003) posit that qualitative research has both positive elements and limitations. As positive elements, qualitative research can generate new theories and recognise phenomena ignored by previous researchers and literature. It provides a rich contextual perspective on the issues that may not be elicited from a standardised questionnaire; it helps to capture what is happening without being judgmental, presents people on their own terms, and conveys their feelings and experiences from their own perspectives (Legard, Keegan & Ward, 2003). However, on the other hand, findings from qualitative research may not be generalisable due to the limited number of participants involved and the stratified purposive nature of the sample. Also due to the small sample size, there is the possibility that the individuals interviewed may be significantly different from the rest of the population. Extensive skill and talent is required when using this strategy and the researcher should be a fast thinker when he or she is in the field (Monette et al., 2011). Researchers cannot simply enter the field and start doing work; instead it is important for them to establish rapport with the participants before commencing the study and this process can be time consuming.

3.4.2 Population and sampling procedures

The targeted population was employees of Epworth Child and Youth Care Centre in Lambton, Ekurhuleni. The researcher used a stratified random sample of 15 participants recruited from Epworth Child and Youth Care Centre in Lambton, Ekurhuleni, South Africa. Participants were drawn from three categories of Epworth Children's Village's employees, namely the therapists, childcare workers and support staff. Five members were recruited from each of the three groups. Furthermore, an interview was conducted with a key informant, namely the manager therapy and assessment centre of the village. A stratified sample is mainly used when a representative sample is required, and also in order to include sub-groups

in the sample in the same proportion as they occur in the target population. According to du Plooy (2009, p. 116) a stratified sample "is drawn when we not only want to draw a representative sample but also want to include sub-groups in the sample in the same proportion as they occur in the target population". Such groups are called strata or known quotas.

A target population can be divided into various strata, based on almost any characteristic or variable, such as various age groups, gender groups, religious groups and/ or political groups, employee categories and / or ranks of employees (Du Plooy, 2009). In this study, employee categories were used and selection was purposive with the researcher approaching the prospective participants and inviting them verbally to participate in the study. The first five participants who agreed to participate in each category were then included. It should be noted that some of the participants may have been HIV positive, this was not an area of investigation and therefore the participants were not required to divulge their status.

Moreover, permission to undertake the study at Epworth was sought from the director of the agency and consent to participate in the study was elicited from the participants. In terms of the inclusion criteria participants needed to be within the three categories of Epworth Child and Youth Care employees, and there was no age limit and / or number of years required in terms of experience. As the researcher works at Epworth, as a social worker, this made it easier to recruit participants. The researcher explained fully that the research was conducted for academic purposes and that participation and refusing to participate would not result in any negative consequences against anyone.

3.4.3 Research tool

Semi-structured interview schedules, Appendix D, were used to address the aim and objectives of the study. Issues that included effects of disclosure and non-disclosure, experiences, roles and recommendations associated with HIV status of children living at Epworth were covered during the interview. According to Legard, Keegan and Ward (2003), semi-structured interview schedules usually involve a clear list of issues to be addressed and questions to be answered. However, there is more flexibility around the sequence in which they are asked and the interviewer can always allow the respondent to speak more broadly about the topics being discussed. Issues that were explored during the interviews included

general understanding of the HIV/AIDS pandemic, the perceived effects of disclosure and non-disclosure of the HIV status to children born with HIV virus living at Epworth, role of social service professionals and recommendations concerning disclosure and non-disclosure of the HIV status of children born HIV positive. A copy of the research tool is set out in Appendix D.

3.4.4 Pre-testing of the research tool

According to Legard et al. (2003), pre-testing is the final stage in interview schedule construction and its purpose is to determine the time taken to administer the interview and to obtain feedback from the respondents regarding any problems in the interview schedule, such as ambiguous or extraneous questions. A pre-test of the research tool was carried out not only to ascertain the applicability of the research questions but also in order to enhance the instrument's validity and reliability. The researcher conducted a pre-test of the research tool with two persons who met the selection criteria but were excluded from participating in the final study. One participant suggested that it would be advisable for the researcher to first establish rapport with the participant instead of proceeding straight into the interview questions as it was anticipated that this approach might not yield the most productive results. Also due to a limited number of employees within each of the three categories, it was suggested that the first question in the interview schedule, which read "How long have you been working here be deleted from the interview schedule as it was anticipated that the authorities might be able to identify participants which might cause participants to give very brief and socially desirable answers in fear of victimisation.

The second participant suggested that question number 6 and 7, which was a continuation of question number 5, be changed from "If yes, what do you think are the effects of disclosure", to read "What do you think could be the perceived effects of disclosure to these children", and "If no, what do you perceive as effects of non-disclosure to them", to read " What do you perceive as effects of non-disclosure ton these children", as it was felt that the original first versions of the questions were too directive. Furthermore, question 3 was also rephrased from "If yes, what is your general understanding about HIV/AIDS", to read "What is your general understanding of HIV/AIDS". Also, because the pre-test interviews were held in the playground, it was found that there were constant disturbances and interruptions during the

session. For example during the researcher's interview with participant number two, two of his friends came to sit adjacent to the participant relax next to us and later during the same interview, children from one of the Epworth houses came running through the jungle gym, making noise which was very disturbing. Thus it was suggested that the researcher conduct his interviews in one of the vacant offices or rooms in the houses. In this way the researcher was able to uphold the ethical principles of privacy and confidentiality. The interviews lasted between 42 and 63 minutes respectively.

3.4.5. Data collection

In-depth, individual, face-to-face interviews were utilised, and all interviews were conducted at the Epworth Child and Youth Care Centre. They were conducted in an environment that was conducive to privacy and sharing. Interviews were conducted in a suitable office and there were minimal levels of disturbances and interruptions. According to Monette et al. (2011), semi-structured interviews allow for more flexibility around the sequence of questions to be asked and also for the interviewer to allow the respondent to speak more broadly about the topic being discussed. In order to enhance reliability of data collected, all participants were asked the same questions and the researcher conducted all the interviews. The duration of the interviews was between 47 and 63 minutes each.

However, there was no audio-taping of the interviews as all participants did not feel comfortable with audio-recording. This was respected as it made participants feel more comfortable and further ensured confidentiality. This could have resulted in the loss of vital information such as precise quotations during the data analysis process and to enhance trustworthiness. Initially the time that was allocated for data collection was four weeks (after the researcher's end of year exams and during school and university vacations); however, due to the fact that some participants were busy during that period, data collection spanned a two and a half month period.

3.4.6. Data analysis

The procedure that was used for data analysis was thematic content analysis, which unpacks the internal logic of the texts analysed and provides a map of the important and interrelated themes contained in the text (Neuman, 2000). Data analysis was based on notes that the

research managed to write during the research process. According to Terre Blanche, Durrheim and Painter (2006), there are various steps that are followed when using thematic content analysis. The first step is familiarisation and immersion, which involves reading through texts many times, making notes, brainstorming and drawing diagrams. This step is followed by inducing themes, which allows for the use of informants' language rather than abstract theoretical language to label different categories.

Coding is the third step that follows, and it entails marking different sections of the data as being instances of, or relevant to, one or more themes identified (Terre Blanche et al., 2006). The fourth step is elaboration, which involves exploring themes more closely together. The final step is interpretation and checking, whereby one goes through the interpretation carefully to try and strengthen weak points after putting together the interpretation (Terre Blanche, et al, 2006). These steps were followed in analysing the data. Credibility, confirmability, dependability and transferability were also considered in order to enhance the trustworthiness of the qualitative data. According to Leininger (1994 in Maxwell & Satake, 2006), credibility refers to the truthfulness, believability and the value of the researcher's findings in representing the real world as perceived by participants. To enhance credibility, the researcher described the setting, targeted population and theoretical framework guiding the study.

De Vos (2004) emphasise the need to ask whether the findings of the study have been confirmed by other persons. To enhance confirmability, the researcher made use of correspondence checking recommended by Pretorius and De la Rey (2004), whereby the categorisation of themes was checked by his supervisor. However, it is acknowledged that using the researcher's supervisor rather than an independent rater, constituted a limitation of the study. Dependability, which is the qualitative equivalent of reliability (de Vos, 2004), was enhanced by having the researcher administer all the interview schedules and following the same steps in analysing all the results. In terms of transferability, the small, stratified purposive sample precluded generalisation of the findings to all social service workers working with children such as those living at Epworth.

3.4.7. Ethical considerations

Avoidance of harm or non-maleficence

The researcher endeavoured to protect participants from any physical or emotional harm. The researcher informed participants beforehand about the potential impact of the study so that they may refuse to participate if they so wish. According to McLaughlin (2007), in any research study, it is important to consider from the outset whether it is likely that participation may be harmful to respondents, and if so, to take evasive action or adopt a contingency plan. Counselling or debriefing sessions are possible ways that can be used to alleviate emotional distress evoked by the study (McLaughlin, 2007). For this reason, the researcher arranged for such a service to be available to participants. However, none of the participants made use of this service.

Informed consent

The researcher provided participant information sheet (Appendix A) and consent forms (Appendix B) which were signed by each participant. The researcher emphasized that participants should ask and seek clarity on anything that they did not understand pertaining to the study. According to Winter and Munn-Giddings (2001), information about the purpose of the study, what form of participation is required, duration of participation, risks, benefits and financial costs should be made available to the participants and their legal representatives. Information should also be given in clear, intelligible and user-friendly language (McLaughlin, 2007). Hepworth, Rooney, Rooney, Strom-Gottfried and Larsen (2010) also emphasize that to facilitate informed consent for persons with hearing, literacy, or language difficulties, social workers should utilise interpreters, translators and multiple communication methods as appropriate. Efforts were made to incorporate these guidelines where necessary.

Voluntary participation

Participation in the study was voluntary and refusal to participate did not hold negative consequences for any of the participants. Participation took place after the information was given to the participants and no persons were forced, bribed or manipulated into participating in the study. In this respect, Rubin and Babbie (1999, p. 51) state that "no one should be forced to participate". All participants were legally and psychologically competent to give

consent and were aware of the fact that they were allowed to withdraw from the study at any given time without any negative consequences as cited by McLaughlin (2007). All the participants voluntarily participated in the study without any form of coercion. In the second paragraph on the participant information sheet, the researcher stated that, "your participation is entirely voluntary and refusal to participate will not be held against you in any way". This was to emphasize that no one should feel forced or coerced to participate in the study.

Confidentiality and Anonymity

Names and other identifying particulars were replaced with codes for purposes of anonymity as outlined by Hepworth et al., (2010). Potgieter (2007) describes confidentiality as one of the most important values of social work practice and research. Confidentiality and anonymity protect the participants' information and respect their worth and dignity at all times regardless of their health, psychological or social status. Confidentiality also entails that only members of the research team will be aware of the identity of participants and will commit themselves to safeguarding all the information provided by the participants. However, the extent and limits of confidentiality were explained to the participants. For example, the researcher could not ensure anonymity because the researcher works at Epworth and also because the interviews were face-to-face and participants were known to the researcher.

Deception

For this research, there was no deception because participants were informed about all the procedures and there was no misleading of participants or hiding of any information. According to Neuman (2000), deception occurs when the researcher intentionally misleads participants by way of written or verbal instructions, the actions of other people or certain aspects of the setting.

3.5. Chapter summary

The chapter provided a detailed description of the research design and methodology. Research questions, the aim and objectives, research strategy, population and sampling procedures, research tools, method of data collection and analysis, together with ethical

considerations, were explicated. This chapter provides the backdrop to the findings presented and discussed in the following chapter.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF RESULTS

4.1 Introduction

This chapter provides the presentation and the discussion of data collected. Descriptive statistics were used to analyse demographic information, while qualitative data were analysed using thematic content analysis in order to analyse and record themes relevant to the research. Findings of the study are discussed in relation to the objectives of the study, the theory and the limitations inherent in the research design and analysis. Themes are illustrated with verbatim responses from participants.

4.2 Demographic information

Table 4.1 Demographic profile of participants (N=15)

Demographic factor	Sub-Category	No.
Gender	Female	11
	Male	4

Table 4.1 represents the demographic profile of the participants. Of the 15 participants who took part in the study, 11 were female and 4 were male, with English, IsiZulu and Southern Sotho being primary languages of communication of participants. The researcher understood all the three languages, and there was no need for an interpreter. In response to a recommendation made by one of the participants in the pre-test, years of experience, educational levels, specific ages and racial groups were not requested and the reason for adhering to this recommendation was that participants would then be identifiable leading to the violation of the confidentiality issue, and this constituted a limitation in terms of data analysis.

4.3 Themes that emanated from the study

Table 4.2 Table of themes that emanated from the study

Category	Themes	Quotations
Social service workers' general understanding of HIV/AIDS	General understanding	"*I understand HIV/AIDS as a life threatening disease that is manageable and requiring support from different service providers". I understand it just like any other chronic disease, it does not scare me, it is just like any other sickness that attacks the human body*".
Social service workers' opinions regarding children born HIV positive	Hard and difficult life	"*I think children born HIV positive suffer a lot and they live a hard and difficult life as they are put on life medication shortly after they are born*".
	Normal human beings	"*These are no difference than children who are born diabetic and / or asthmatic, because both diseases are life threatening and chronic just like HIV/AIDS, we just need to see them as normal children, nothing else*".
	Need for education about condition	"*These are no difference than children who are born diabetic and / or asthmatic, because both diseases are life threatening and chronic just like HIV/AIDS, we just need to see them as normal children, nothing else*".
	Evidence of parents' ignorance	"*To me their condition was due to ignorance from their parents' side who failed to protect them from the virus*".
Perceptions regarding disclosure of status	Enhanced responsibility and adherence to medication	"*If children are told about their positive HIV status, they will know how to live responsibly and also understand the importance of taking medication regularly without fail so as to live a healthy and prolonged life*".
	Minimisation of un-answered questions and suspicions	"*Most information that I have come across about HIV/AIDS...emphasise on promiscuity being the major contributor to HIV infection, and this can be very confusing to a child who has never been involved in a sexual relationship... and might result in the child having a number of questions that he or she cannot find answers to...therefore remaining confused and suspicious*".
	Helps children to understand why they do not have parents	"*Disclosing to these children will help them understand why they do not have parents and why they are orphans and staying in a child and youth care centre...especially those who were abandoned when they were very young*"
	Disclosure might take away children's happiness	"*Childhood is a time to be happy...there is no need to burden children with sadness and worry. For me, a child who knew that he or she is HIV positive will not be able to enjoy his or her childhood in a carefree manner*".
Social service workers' perceptions regarding non-disclosure of HIV status to children	Non-disclosure might increase HIV prevalence rate and new infections	"*Not disclosing to these children makes me feel concerned and afraid that as they grow up they might infect others unknowingly, thereby increasing HIV prevalence rate and also new infections*".
	Non-disclosure protects children from despair, stigma, discrimination and rejection	"*For me, not telling children protects them from despair and stigma and from being discriminated by their peers when playing*"
	Non-disclosure makes adherence to medication difficult	"*Winning them to voluntarily take their medication required a lot of energy, hard work and convincing statements, as if they do it for us yet it is for their own good*".

Social service workers' experiences regarding disclosure of children's HIV positive status	Never attempted to disclose	*"To me disclosure is not a process that any person can perform, I think it requires advanced education and training so that all emotional issues that might come up during the process might be dealt with without causing damage to the infected children".*
	Attempt to disclose made	*"When I disclosed to a child, the child decided to let the whole village to know that he or she is HIV positive and after that I observed that I observed that the child became embarrassed and humiliated…and peer association changed".*
Perceptions of the roles played by social service workers regarding disclosure of HIV status to children born HIV positive	Education and counselling	*"I think that one of the roles is to educate and counsel these children so as to boost their self-esteem and confidence, and also teaching them survival strategies and skills of dealing with any negative issues that might confront them following disclosure".*
	Protection and advocacy	*"It is the duty of social service workers to protect children regardless of their HIV status and to advocate on behalf of children, who are HIV positive, for policy guidelines that encourages disclosure"*
Recommendations concerning disclosure of children's HIV positive status	Disclosure to be done after educating the child about HIV/AIDS	*"Children should be educated about the disease before disclosure is done, as this might create a general understanding about their condition together with ways of keeping a healthy body".*
	Need for the development of a manual with guidelines for disclosure	*"Some of us have been trained more on childcare and protection and I think for us to be actively involved in the process of disclosure, there is need to be trained and / or to have a manual that will help us through the process in terms of providing supportive counselling to these children as we spend much of our time with them".*
	Qualified and competent social service workers to carry out disclosure	*"I think for disclosure to be done effectively we need qualified people to do it, especially those who directly interact with children because for me I can only come in when the child asks or seek clarity of some kind".*
	Need to collaborate with health care institutions when undertaking disclosure	*"I recommend that we involved healthcare professionals from the clinics and hospitals that these children attend so that while we do supportive counselling and look into the psychosocial needs of these children, they can also have an opportunity to be educated by people who will focus on the medical side".*

4.4 Social service workers' general understanding of HIV/AIDS
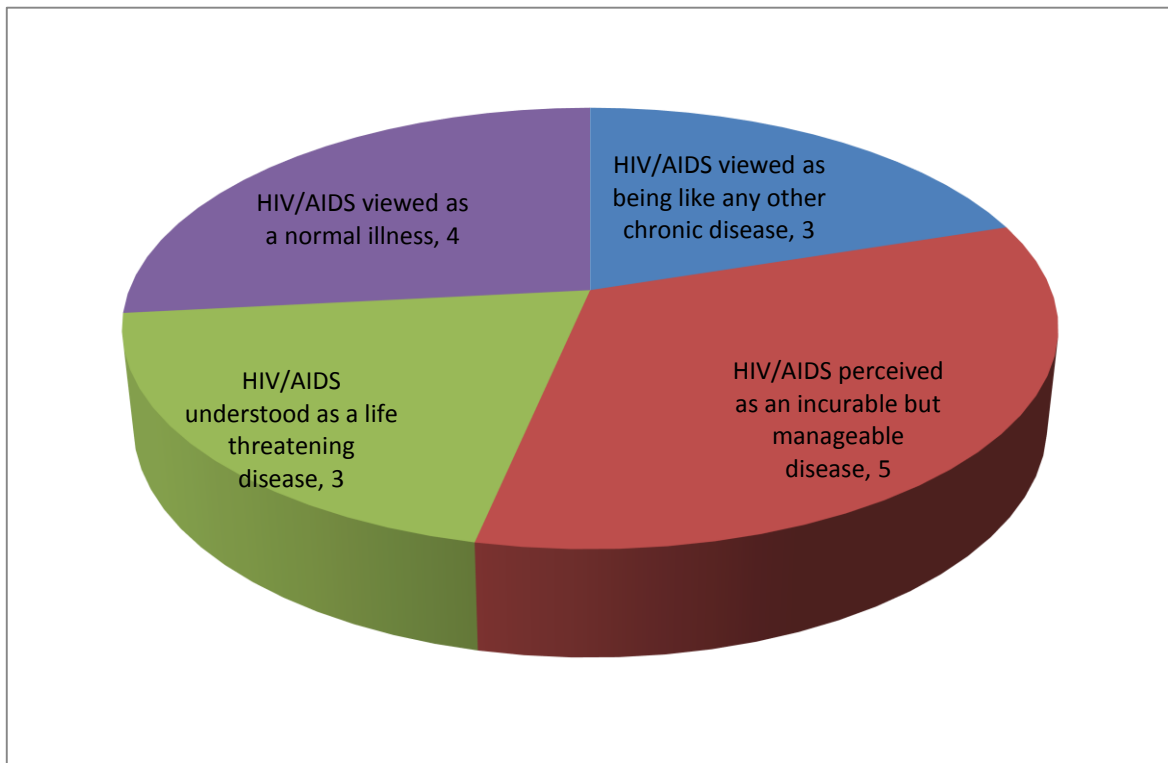
Figure 4.1 Social service workers' general understanding of HIV/AIDS (N=15)

The findings revealed that all participants from the different groupings, especially therapist and child care workers understood HIV/AIDS as an incurable but manageable disease and four participants understood HIV/AIDS as a normal condition and / or illness. It also emerged that three participants viewed HIV/AIDS as a life threatening disease. One of the participants explained:

> "*I understand HIV/AIDS as a life threatening disease that is manageable and requiring support from different service providers*".

Again, three participants understood HIV/AIDS as being just like any other chronic diseases that affects and disturb people's social functioning. One participant commented:

> "*I understand it just like any other chronic disease, it does not scare me, it is just like any other sickness that attacks the human body*".

The participants generally therefore demonstrated an understanding which acknowledged the seriousness of HIV/AIDS, but at the same time retaining a sense of optimism and hope about its management.

4.5 Social service workers' opinions regarding children born HIV positive
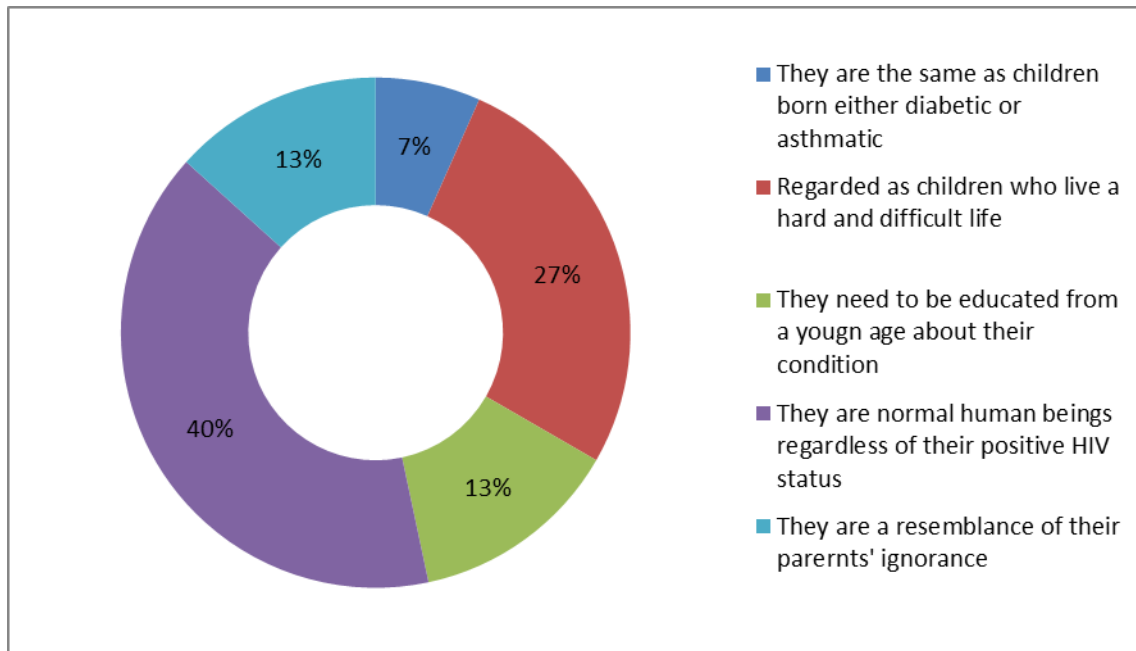
Figure 4.2 Social service workers' opinions regarding children born HIV positive (N=15)

Five participants indicated that they regard children born HIV positive as ordinary human beings and normal, regardless of their positive HIV status. However, four participants revealed that they regard children born HIV positive as children who live a hard and difficult life due to the fact that they have to start taking life treatment from the day they are born until they die. She explained:

"To me they are just like any other normal human being; there is nothing wrong with them".

and

"I think children born HIV positive suffer a lot and they live a hard and difficult life as they are put on life medication shortly after they are born".

Furthermore, there was also a concern around the importance of adherence to medication by the children. Two participants indicated that they think that children born HIV positive need to be educated about their condition or their HIV positive status at a young age. They argued that this would be important in order to encourage and ensure adherence to medication. Most of the participants had described children as being normal and that they should not be seen as different. An example of such a view comes from one of the participants who stated:

> *"These are no difference than children who are born diabetic and / or asthmatic, because both diseases are life threatening and chronic just like HIV/AIDS, we just need to see them as normal children, nothing else".*

Another aspect that was indicated by participants was the awareness around mother to child transmission and how the fact that some of the children were born with HIV would point to the reality that they had HIV positive parents, who had not taken full responsibility to protect them from getting the disease. One of the participants stated:

> *"To me their condition was due to ignorance from their parents' side who failed to protect them from the virus".*

Mother to child transmission of HIV is an area that is also characterised by stigma and blame. Heyns and Swanevelder (2005) highlight that HIV is transmitted to approximately one third of babies of HIV positive mothers if there is no medical intervention, such as the use of antiretroviral drugs, obstetric practices including caesarean delivery and safe infant feeding practices. Although perceptions may be that this form of transmission may be due to neglect and irresponsibility, the reality is also that such transmission of HIV cannot only be blamed on the parent. This source of stigma may be particularly difficult to guard against as social service workers may consider such stigma to be valid, it would be equally damaging to the child concerned in terms of feelings of rejection and lack of care by parents.

4.6 Perceptions of social service workers regarding HIV status disclosure to children born HIV positive

The themes displayed in figure 4.3 were identified with respect to the perceptions of social service workers regarding HIV status disclosure to children born HIV positive living at Epworth child and youth care centre.
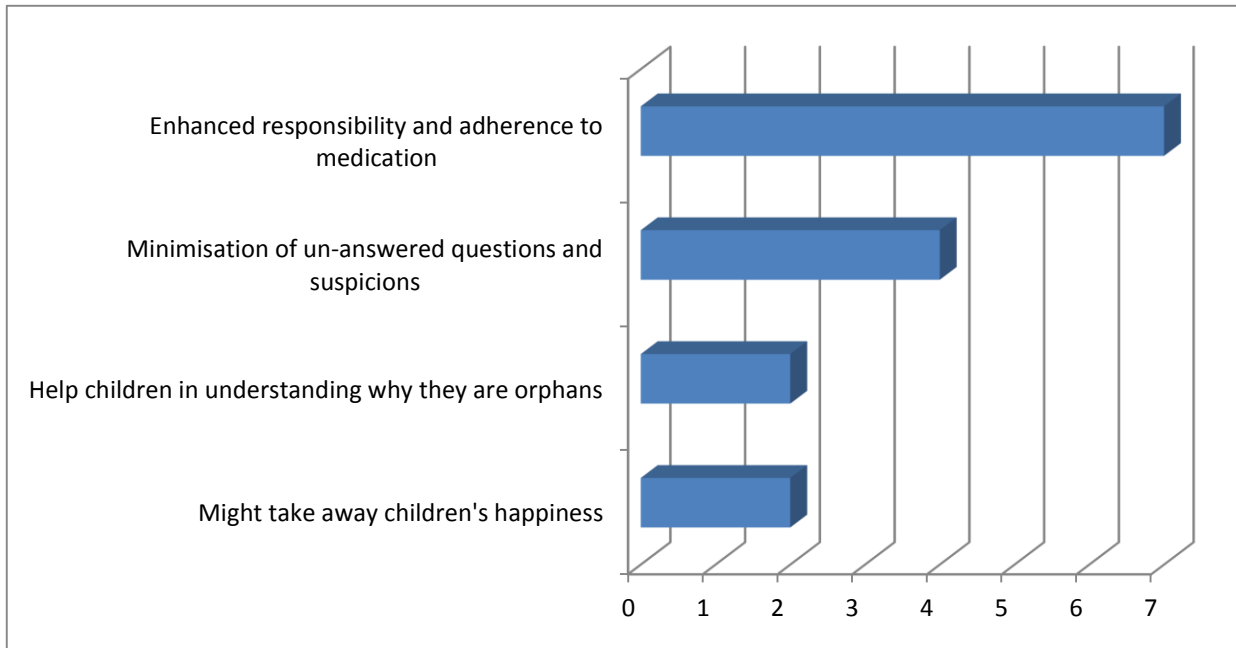
Figure 4.3 Social service workers' perceptions regarding HIV status disclosure to children born HIV positive living at Epworth (N=15)

Enhanced responsibility and adherence to medication

A theme that emerged from the analysis of responses, and was mentioned by seven participants, was the notion of enhanced responsibility and adherence to medication. This theme was starkly captured in the following response:

> *"If children are told about their positive HIV status, they will know how to live responsibly and also understand the importance of taking medication regularly without fail so as to live a healthy and prolonged life".*

This response emphasises the need for disclosing children's HIV status so as to protect them together with those with whom they interact. Waugh (2003) also stated that through the process of disclosure, the child should be helped to learn strategies to prolong a healthy life, including adherence to ART, what the risk factors are, responsibilities now and in the future, as well as to cope with possible negative reactions of others. The views of participants regarding the benefit of enhanced understanding and adherence to medication are consistent with the findings by Bikaako-Kajura et al., (2006) that children who knew their HIV status

became self-motivated to adhere to their medication as they were aware of the reason why they were taking medication.

Minimisation of un-answered questions and suspicions

Four participants in the study commented that disclosing HIV status to children born HIV positive can result in minimised unanswered questions that children might be having about their condition. This theme was encapsulated in the response by one participant who stated:

> *"Most information that I have come across about HIV/AIDS in both print and electronic media emphasise on promiscuity being the major contributor to HIV infection, and this can be very confusing to a child who has never been involved in a sexual relationship… and might result in the child having a number of questions that he or she cannot find answers to…therefore remaining confused and suspicious".*

This theme is related to what Naeem-Shaik and Gray (2005) refer to as partial disclosure, whereby the child is not fully aware of his or her HIV disease but is suspicious, asks questions from the caregiver about the disease and the drug, and, in many cases assumes that the drug is a cure. However, if disclosure is done, such questions, confusions and suspicions can be minimised.

Helps children to understand why they do not have parents

The responses of three participants suggested that by knowing their HIV status, children born HIV positive and living at Epworth can have a good sense of understanding on why they do not have parents and are institutionalised. Two participants commented:

> *"Disclosing to these children will help them understand why they do not have parents and why they are orphans and staying in a child and youth care centre…especially those who were abandoned when they were very young"*

and

> *"…sometimes they are so concerned about their parents not visiting them and even though I explain to them that their mother or father passed away, they do not understand why".*

This finding is related to literature, where Naeem-Shaik and Gray (2005) emphasized that waiting for a better time to disclose may be appropriate, but the child may also be concerned about why the parent died and what that means for him or her. It is during this period that children may be educated about their condition and also have things clarified concerning the death of his or her parents. A holistic approach to the child's needs for knowledge and dealing with grieving processes would thus be facilitated.

Disclosure might take away children's happiness

In contrast to the general views about disclosure of HIV status to the children concerned, two participants indicated that they were of the view that disclosing children's HIV positive status might take away their happiness. This finding was encapsulated in the response of one participant who said:

> *"Childhood is a time to be happy...there is no need to burden children with sadness and worry. For me, a child who knew that he or she is HIV positive will not be able to enjoy his or her childhood in a carefree manner".*

This response further indicated that disclosure is perceived to have the potential of creating unhappiness in a child's life as it might be partnered with precautions and restrictions that would not allow a child to live a carefree and developmentally appropriate life. It also seems to indicate a perception that is common, that HIV/AIDS does not include hope and a positive approach to those who are negative as there are constant issues about happiness related to death and dying due to the pandemic. Bikaako-Kajura et al., (2006) also highlights that how children experience and understand illness and death at different ages and levels of development varies greatly. This in turn affects their capacity to understand their treatment, how much they can be expected to co-operate with treatment and what they can manage in self-care. Gradual understanding that death is permanent, final and irreversible, can result in children expending much energy on issues concerning their health other than concentrating on living a carefree and simple life. However, this finding may also be an indication of social service workers' own views around disclosure and possibly their own problems and discomforts at HIV as an incurable illness.

4.7 Social service workers' perceptions regarding non-disclosure of HIV status to children

Figure 4.4 reflects the themes that were identified in respect to social service workers' perceptions regarding non-disclosure of the HIV status to children born HIV positive.
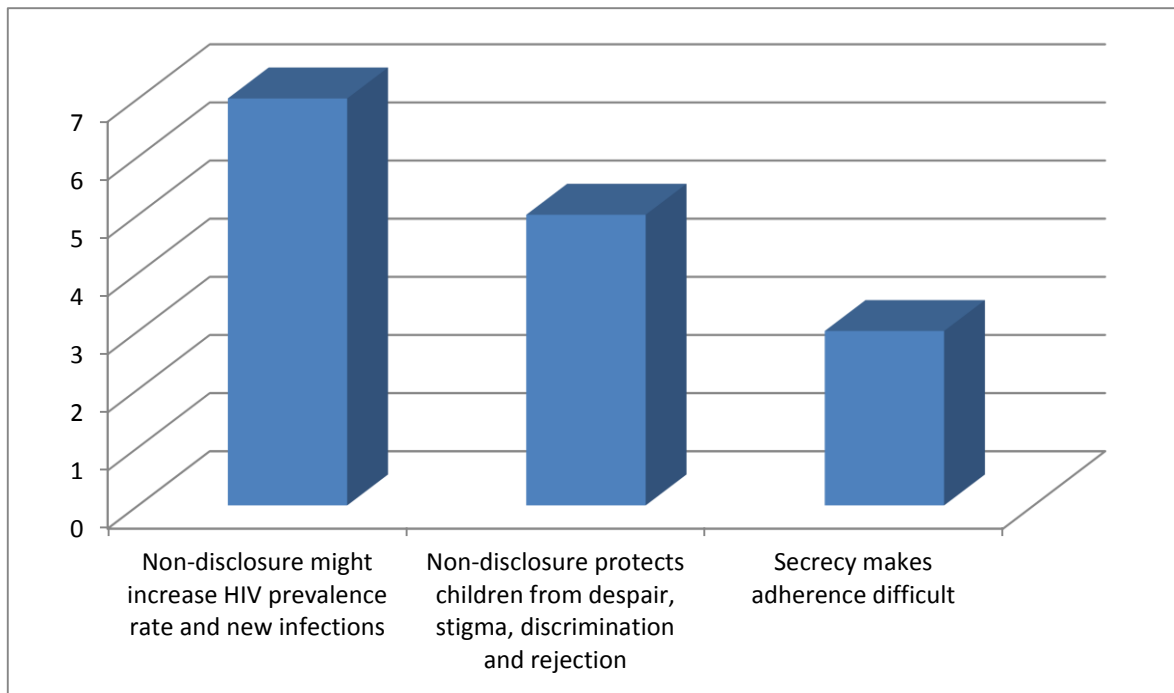
Figure 4.4 Social service workers' perceptions regarding non-disclosure of HIV status to children born HIV positive living at Epworth child and youth care centre (N=15)

Non-disclosure might increase HIV prevalence rate and new infections

The responses of seven social service workers indicated that they have fear and concern that non-disclosure of a child's HIV positive status might contribute to the already high HIV prevalence rate and new infections among children. This theme was well captured in the following response:

> *"Not disclosing to these children makes me feel concerned and afraid that as they grow up they might infect others unknowingly, thereby increasing HIV prevalence rate and also new infections".*

This finding highlights the fact that non-disclosure creates a sense of concern and uneasiness in social service workers' minds as they perceive that it can lead to increased incidents of prevalence and new infections among children. Also, to further illustrate this theme, one respondent commented:

"Nowadays HIV is manageable due to the anti-retroviral therapy (ART), and children no longer die at a young age but they mature into adolescence and become sexually active and if they are not told about their HIV positive status, they might infect their peers and this worry and concerns me a lot".

These findings can be related to literature where Pantell (2006) emphasised that with the growing access to ART, HIV infected children survive to older ages, and in turn discussing HIV status with infected children is most likely to become an important issue in paediatric HIV care. This was also highlighted by one participant who said:

"Some children have already reached puberty and others will be in the puberty stage very soon and by not telling them and educating them extensively about their condition, we are just encouraging the spread of the HIV related virus".

Non-disclosure protects children from despair, stigma, discrimination and rejection

On the other hand some responses revealed that some of the social service workers (five out of the fifteen participants) indicated that non-disclosure acts as a protective measure to the children from different forms of discrimination, stigma and rejection. One participant commented:

"For me, not telling children protects them from despair and stigma and from being discriminated by their peers when playing"

and

"...even here in the village some children tease those who take medication and make fun out of them, so it is better to protect these children from being rejected and discriminated against by keeping their status undisclosed".

These responses suggested that some social service workers perceived non-disclosure as a form of protecting HIV positive children from being stigmatised, discriminated against and rejected due to their positive HIV status. These findings concur with literature where UNAIDS (2003) emphasized that HIV-related stigma and discrimination build upon and reinforce existing prejudicial and stigmatising thoughts that frequently lead a person to do or not to do something that denies services or entitlements to another person. Moreover, UNAIDS (2003), highlighted that discrimination can lead to depression, lack of self-worth and despair for people living with HIV even though they are not the only ones at risk form this fear and prejudice.

However, instead of encouraging non-disclosure as a protective measure, UNAIDS (2003) suggested that there is need to confront and fight discrimination and stigma experienced by those infected and affected by the HIV virus so that fear, shame, ignorance, labelling and injustice can be eradicated.

Non-disclosure makes adherence to medication difficult

The study also highlighted the fact that non-disclosure creates difficulties in children's abilities to adhere to medication regimes. The participants spoke about the difficulties that they sometimes experience at the time when children are being given their pills. Social service workers indicated that this would be the time that difficult behaviours emerged. Some children tended to use the taking of medication to act out, manipulate, threaten and seek attention, partly -because of the little knowledge that these children have about their HIV status. This theme was encapsulated in the following responses:

> *"Sometimes we end up using force and verbal abuse in order to get some of these children to drink their pills…and this is not a good thing to do but we will be left with no choice"*

and

> *"Some children drink their pills and keep them in their mouth under their tongue, only to later on spit the medication in the bathroom besides telling them time and again that medication is important as it keeps their bodies healthy"*.

One participant also commented:

> *"Winning them to voluntarily take their medication required a lot of energy, hard work and convincing statements, as if they do it for us yet it is for their own good".*

The first response suggested that children are sometimes coerced to take their tablets and it may be an indication that these children are not self-motivated. The process of taking medication then seems to become a way that can emotionally blackmail social service workers to seek attention or engage in power struggles. The responses also suggest that children were still not aware of how important medication was, evidenced by the lack of self-drive and responsibility when it came to medication. Lack of self-responsibility around adherence to medication, even among those who are fully aware of their HIV status, is a complex and difficult issue. This is echoed in the findings from a study that was done in Uganda by Bikaako-Kajura et al., (2006) around incentives for adherence to medication regimes, where it was found that provision of special foods, such as sweetened fruit juice, ripe bananas, cakes and chocolate acted as an adherence incentive for most of the respondents who participated in the study.

4.8 Social service workers' experiences regarding disclosure of children's HIV positive status
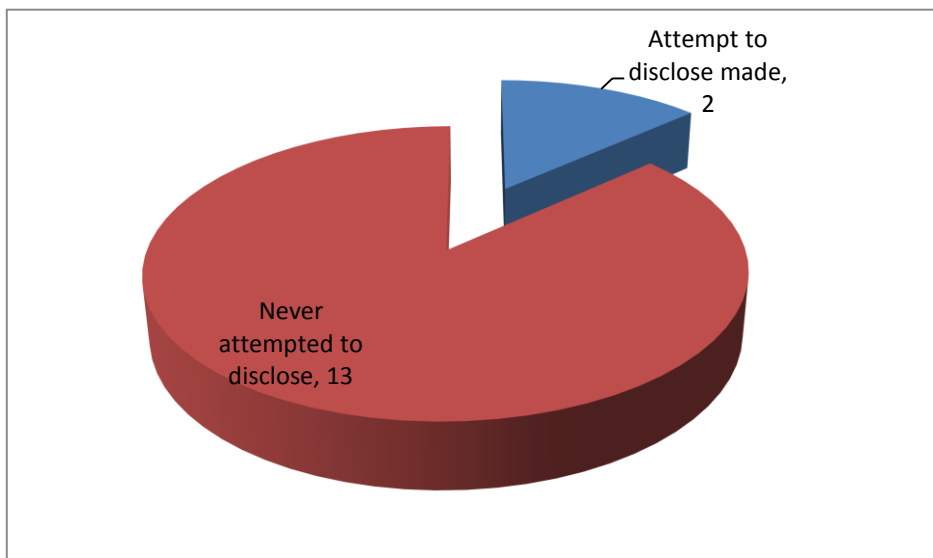
Figure 4.5 Social service workers' experiences after attempting to disclose the child's HIV positive status (N=15).

Never attempted to disclose

Almost all of the participants from all three groupings of Epworth employees who participated in the study revealed that they had never attempted to disclose the child's HIV positive status. Four participants from all groupings of the employees who had never attempted to disclose did not have any specific reason for their non-disclosure. However, of the remaining nine participants, five indicated that disclosure was not part of their job description, while four of them highlighted that they required more advanced training, experience and expertise for them to carry out such a sensitive task. This theme was encapsulated in the following response:

> *"I perform a lot of different tasks, but disclosure of children's HIV status is not part of my job description in this organisation"*

and

> *"To me disclosure is not a process that any person can perform, I think it requires advanced education and training so that all emotional issues that might come up during the process might be dealt with without causing damage to the infected children".*

These findings might be indicating the need for policies and guidelines concerning disclosure so as to equip social service workers with necessary skills and expertise that they might need when carrying out such tasks. This is in line with the guidelines set by the SACSSP (2007), where it is highlighted that social service professions, especially social workers need to practice and perform duties that are within their area of expertise and competence. However, even though this could be a reflection of the need for policies and guidelines, it can also seem to be an indication of discomfort among social service workers in tackling disclosure.

Attempt to disclose made

Two participants who indicated that they had disclosed children's HIV status to them, expressed concern that the children, when told about their positive HIV status, were unable to

keep it as private and confidential information but that they spread the news all over the village. This makes it difficult to protect children from stigma and discrimination. This theme was captured when one of the participants said:

> *"When I disclosed to a child, the child decided to let the whole village to know that he or she is HIV positive and after that I observed that I observed that the child became embarrassed and humiliated…and peer association changed".*

Also, the other participant emphasised that when disclosure is to be made, it should be partnered with counselling and proper education and support to the child. The participant commented:

> *"I think it is very important that before disclosure is attempted, the child should be prepared, properly counselled, educated and to make it a point that all the questions that he or she will be having, get answered so as to avoid putting the child at risk of being stigmatised or discriminated against, by his or her failure to keep his or her status confidential".*

This finding concurs with literature where Pantell (2006) stated that parents and guardians may have reservations because of concern over the child's reaction and fear that the child may tell others leading to child together with the whole family being exposed to stigma and rejection.

4.9 Perceptions of the roles played by social service workers regarding disclosure of HIV status to children born HIV positive
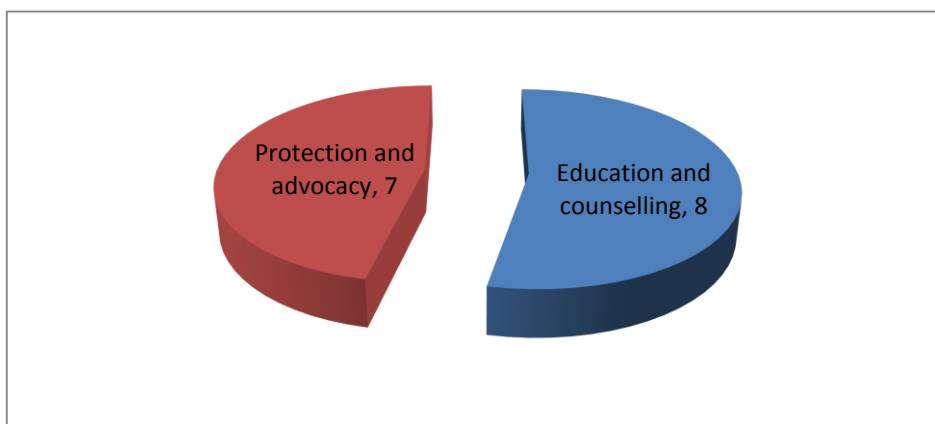
Figure 4.6 Perceptions of the roles played by social service workers regarding disclosure of HIV status to children born HIV positive living at Epworth (N=15).

Education and counselling

The provision of counselling education was highlighted by seven respondents. It was noted that social service workers were perceived to be of great help to children born HIV positive as they were viewed as capable of providing these children with a wide range of services including counselling and educating them on different techniques that they could use to deal with the outside world. This theme was articulated by one participant who said:

> *"I think that one of the roles is to educate and counsel these children so as to boost their self-esteem and confidence, and also teaching them survival strategies and skills of dealing with any negative issues that might confront them following disclosure".*

This finding confirmed that there were initiatives in place that were designed to help these children to deal with different issues that they might encounter due to disclosure. Counselling, according to Zastrow (2010) is also important as it covers almost all emotional and interpersonal problems that the client might be presenting. Also the provision of education helps to equip these children with the necessary skills that might be of help to them when interacting with others.

Protection and advocacy

This theme was reflected in the responses of seven of the fifteen social service workers who participated in the study. An example of this theme was encapsulated in the following responses:

> *"It is the duty of social service workers to protect children regardless of their HIV status and to advocate on behalf of children, who are HIV positive, for policy guidelines that encourages disclosure"*

 and

> *"As a social service worker I believe that it is my duty to protect all children from any form of harm, and when it came to children born with HIV, social service workers*

need to be proactive and make it a point that these children are protected from any form of stigma and discrimination that might hinder them enjoying life to its fullest and exercising their capabilities to their full potential as well".

This response suggested that social service workers at Epworth understood their roles and duties that they should perform when dealing with sensitive issues like HIV and children and their level of involvement when dealing with disclosure and nondisclosure of the HIV status to children born HIV positive. According to Zastrow (2010), social service workers, for example, social workers recognise an obligation to advocate for the powerless, oppressed and the dispossessed, and the commitment to the belief that society has a responsibility in respect of all of its members to provide security, acceptance and satisfaction of basic cultural, social and biological needs. Furthermore, Mahery et al., 2011 maintains that social service workers have a moral responsibility to work towards eradicating discrimination so as to protect the civil rights of clients and preserve human dignity and self-respect.

4.10 Recommendations concerning disclosure of children's HIV positive status

Disclosure to be done after educating the child about HIV/AIDS

All participants from different groupings revealed that there was need to educate children about HIV/AIDS prior to disclosing their HIV positive status. This was to help create a general understanding about the virus and the disease itself, together with ways of maintaining a healthy body. One participant commented:

> *"Children should be educated about the disease before disclosure is done, as this might create a general understanding about their condition together with ways of keeping a healthy body".*

Education prior to disclosure was regarded as an important part of the process due to the fact that there seems to be a common perception that HIV/AIDS was like a death sentence, thus there was need to demystify the perception. This was captured when one participant said:

> *"Some television advertisements and awareness messages about HIV are so negative that when people hear about HIV they see death instead of a condition that can be managed, so it is our duty as social service workers to help demystify the perception".*

Need for the development of a manual with guidelines for disclosure

The responses from all participants in different groupings of employees, especially childcare workers and support staff   indicated that there was a need to develop a training manual with guidelines on how disclosure can be carried out. This was due to the fact that employees from these groupings felt that they were not trained on how to handle disclosure of HIV status to children, thus they felt the need for a manual with guidelines. One respondent highlighted that:

"Some of us have been trained more on childcare and protection and I think for us to be actively involved in the process of disclosure, there is need to be trained and / or to have a manual that will help us through the process in terms of providing supportive counselling to these children as we spend much of our time with them".

This response suggested that within the organisation there were some tasks that are performed by a certain group of employees and that HIV status disclosure was therefore requiring different groupings to work together regardless of different roles that they typically play on a day-to-day basis. However, with written down guidelines, it was anticipated that all different categories of employees might be able to play a role during the process. This was captured when one participant said:

> *"Children spend more time with us, and it is important that we become equipped with necessary skills and expertise that will help us to deal effectively with all the questions that the child might have following disclosure, and the other thing is that these children have developed a good relationship with us, so they might be able to ask questions in a more relaxed environment".*

Qualified and competent social service workers to carry out disclosure

All participants from different groupings, especially support staff revealed that there was a need for disclosure to be done by qualified and competent personnel, especially those who work directly with the children. He commented:

"I think for disclosure to be done effectively we need qualified people to do it, especially those who directly interact with children because for me I can only come in when the child asks or seek clarity of some kind".

This response might have suggested that social service workers are clear with the roles that they play within the organisation. However, this might also be an indication that social service workers were also not ready to disclose and / or to be part of the process as it might be creating discomfort within them as well.

Need to collaborate with health care institutions when undertaking disclosure

The need for a collaborative effort with healthcare institutions and personnel was highlighted by all respondents from different groupings, siting incorporating different views from different professions as one of the ways that can help children to best understand HIV as it will be a combination of a social and a medical perspective to disclosure. This theme was articulated in the following response:

"I recommend that we involved healthcare professionals from the clinics and hospitals that these children attend so that while we do supportive counselling and look into the psychosocial needs of these children, they can also have an opportunity to be educated by people who will focus on the medical side".

This response suggested a multidisciplinary approach to disclosure with each profession focussing on a different issue. This recommendation concurs with findings from a study that was done in Uganda on disclosure and adherence to daily drug regimens among HIV-infected children by Bikaako-Kajura et al., (2006) where it was found that health care professionals play an important role as they explain the medical side regarding the importance of regularly taking medication.

4.11 Chapter Summary

This chapter provided the presentation and discussion of the findings that emanated from the study. The perceptions of social service workers regarding HIV status disclosure and nondisclosure to children born HIV positive were discussed together with whether or not social service workers have attempted to disclose and their experiences thereafter. Also, the

perceptions of the roles played by social workers concerning HIV status disclosure and nondisclosure to children born HIV positive and recommendations for disclosure were also explicated. A summary of main findings, conclusions and recommendations are presented and discussed in the following chapter.

CH APTER FIVE

MAIN FINDINGS, CONCLUSIONS AND RECOMMENDATION

5.1 Summary of the main findings

The research study explored the perceptions of social service workers about the effects of HIV status disclosure and non-disclosure to children born HIV positive living at Epworth child and youth care centre.

Knowledge and perceptions around HIV

The findings revealed that social service workers, working for Epworth who participated in the study had good and positive knowledge about the general understanding of HIV/AIDS and children born with the virus. They regarded these children as normal human beings similar to any other child born with a chronic illness like diabetes and asthma. However, even though HIV was viewed as a normal condition, participants revealed that they were also aware that it is incurable and life threatening, while at the same time it can be manageable.

Perceptions around disclosure of children's HIV status

Different perceptions were expressed with regard to HIV status disclosure and included both positive and negative comments. Some social service workers perceived that disclosure enhanced responsibility and adherence to medication, minimised suspicions and allowed children the opportunity to understand why they do not have parents, while other social service workers indicated that disclosure can take away the child's childhood happiness, thereby denying the child an opportunity to live a carefree life.

However, the fact that participants from all groupings perceived that 'disclosure can take away childhood happiness', may also be indicative of their own fears, problems and discomfort at HIV as an incurable illness as these views seemed to be based solely on their own views around disclosure.

Perceptions around non-disclosure of children's HIV positive status

Participants revealed that non-disclosure was viewed as a way of protecting HIV positive children from despair, discrimination and stigmatisation, and from being rejected by their

peers. This was due to the anticipation that children were perceived as unable to keep secrets, which was going to make it difficult for them to keep their HIV positive status private and confidential. However, this might also be viewed as denying children the opportunity to exercise their sense of agency and taking personal responsibility. It could be argued that by seemingly 'protecting' children, at the same time social service workers might be denying them their right to know crucial information about their own health and to exercise their freedom and competencies.

Participants in all the occupational categories that were included (childcare workers, therapists and support staff) also perceived non-disclosure as a challenge as it was feared that non-disclosure could result in increased new infections among children. This was seen to be due to the fact that HIV positive children no longer die at a young age, as with proper treatment, they can mature into adolescence and adulthood. This meant that if they were not properly educated and counselled around the issues of HIV, they could pose a risk to others and to themselves. Increased HIV prevalence and difficulties in adhering to medication were other comments that respondents raised against non-disclosure. Furthermore, it was found that non-disclosure strained the relationship between the child and the caregiver, since the caregiver needed to apply a combination of force and persuasion to get the child to adhere, leading to coercion and in some cases to children's purposeful non-adherence.

The role of social service workers in disclosure of children's HIV status to them

Furthermore, some social service workers indicated that they had never attempted to tell a child about his or her positive HIV status and this was either due to the position that they held at the organisation or their level of education and expertise. However, for the few participants who indicated that they have attempted to disclose or who have once disclosed the child's HIV positive status, experienced that children, when told about their HIV positive status, were unable to keep the information to themselves. This could therefore result in the child's HIV status being known to others in the children's village, compromising the child's right to confidentiality and privacy. Moreover, the study revealed that social service workers of Epworth child and youth care centre could play various important roles when it came to HIV status disclosure or non-disclosure to children born HIV positive living at Epworth. These

included protection and advocacy, together with education and provision of counselling as support strategies to children born with the virus.

Recommendations from social service workers about the handling of disclosure of children's HIV status in a childcare setting

The participants also gave recommendations regarding the process and manner of disclosure. They indicated that disclosure needed to be viewed as a multidisciplinary issue that required different role players including health care professionals who were perceived to be well knowledgeable in terms of medical explanation. Moreover, they indicated that disclosure should be done at a stage where the child is able to understand and comprehend the information.

5.2 Conclusions

It is clear that the disclosure of children's HIV status to them is a complex issue that requires careful thought and planning. Both negative and positive consequences may follow on the disclosure and non-disclosure. The arguments for disclosing children's HIV status to them expressed by social service workers of Epworth were that HIV status disclosure can enhance responsibility and adherence to medication; minimise suspicions and confusion that the children concerned may have relating to their HIV status; children's grieving processes could be facilitated and they could be helped to understand and come to terms with the reasons for their parent/s' death.

Although social service workers generally believed strongly that HIV status disclosure was important and necessary, there were some concerns around the consequences of such disclosure. Perceptions in this regard included that children may find it difficult to cope with the knowledge; that the knowledge would impose a heavy burden on the children concerned affecting the 'carefree nature of childhood', and that there would be an increased risk of stigma in a community such as a children's home or child and youth care centre setting. Of critical importance were the procedures and processes involved in managing disclosure of HIV in the setting. There was a need for a policy as well as thorough training to manage the complex dynamics involved. Furthermore, it was recommended that although the responsibility for such disclosure should rest with therapists, it should also occur within a

multidisciplinary team approach with clear planning and collaboration between the various team members.

In conclusion, as much as it would seem that HIV/AIDS is regarded as being like any other chronic diseases, it does carry complexities when it came to disclosure and non-disclosure of the HIV positive status, especially to children born HIV positive. While organisations such as Epworth child and youth care centre are offering excellent services to children in the area of alternative care and family reunification, it is important that the difficult issue of HIV status disclosure be managed through the development of policy guidelines that encourage disclosure without creating the possibility of increased stigmatisation and discrimination for these children.

5.3 Recommendations

Based on the aforementioned findings and conclusions, the following recommendations are made:

5.3.1 Recommendations for community educative and awareness programmes

- Although there have been extensive awareness campaigns regarding HIV and AIDS, there is a need for innovative, culturally appropriate programmes that target the specific needs of children born HIV positive particularly those residing in child and youth care centres.

- Community programmes should be introduced that will involve both HIV positive and negative children in residential care centres so as to encourage integration and reduce the effects of stigma associated with being born HIV positive living in a child and youth care centre.

5.3.2 Recommendations for policy and practice changes regarding disclosure and non-disclosure of HIV status to children born HIV positive living in child and youth care centres

- It is recommended that policy guidelines concerning HIV status disclosure to children born HIV positive living at Epworth be reviewed and developed, to allow a more flexible and open communication with regards to the issue. For example,

there is a need to incorporate all categories of employees in the planning and management of the disclosure process so that children may be supported by all the various social service workers that they encounter.

- The developmental stage and age of the child concerned should be taken into account and so an individual assessment of a child's readiness to deal with the disclosure would need to occur. However, there should be a general policy that children should have their HIV status disclosed to them within the context of a supportive, therapeutic environment.

- Policies and processes around disclosure will need adequate thought, consideration and training of all staff to be clear about the various roles played in this regard.

- Children should be allowed the freedom to exercise their rights regarding access to information about their health status so they can, together with the childcare centre, also have control and agency over the management of possible peer and other forms of stigmatisation.

5.3.3 Recommendations for future research

- As the research was conducted at Epworth child and youth care centre only, it is proposed that similar studies be carried out in other child and youth care centres in different parts of the country in order to explore the issues further and incorporate the views and practices from other contexts.

- The present study was based on a small, stratified, purposive sample which precluded generalisation of the findings to the broader population of social service workers working in institutions that also cater for children born HIV positive. The study would be able to make more generalised findings if it were replicated using larger, more representative samples. It would also enable the exploration of more specific views and roles of the various occupational categories of social service workers without concerns about confidentiality and identification of specific participants.

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APPENDIX A

PARTICIPANT INFORMATION SHEET

Good day,

My name is Nkosiyazi Dube and I am a Masters student registered for the degree Master of Arts in Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research into the perceived effects of HIV status disclosure and non-disclosure to children born HIV positive living at Epworth Child and Youth Care Centre in Ekurhuleni, South Africa. It is hoped that this information may help in enhancing intervention strategies of social service professionals responsible to carry out such tasks. I therefore invite you to participate in my study. Your participation is entirely voluntary and refusal to participate will not be held against you in any way. If you agree to take part, I shall arrange to interview you at a time and place that is suitable for you. The interview will last approximately one hour. You may withdraw from the study at any time and you may also refuse to answer any questions that you feel uncomfortable with answering. With your permission, the interview will be tape-recorded. No one other than my supervisor will have access to the tapes. The tapes and interview schedules will be kept for two years following any publications or for six years if no publications emanate from the study. Please be assured that your name and personal details will be kept confidential and no identifying information will be included in the final research report. As the interview will include sensitive issues, there is the possibility that you may experience some feelings of emotional distress. Should you therefore feel the need for supportive counselling following the interview, I have arranged for this service to be provided free of charge by Mrs. Linda Smith. She may be contacted at 011 717 4472. Please feel free to ask any questions regarding the study. I shall answer them to the best of my ability. I may be contacted on 073 093 3485. Should you wish to receive a summary of the results of the study; an abstract will be made available on request.

Thank you for taking time to consider participating in the study.

Yours sincerely

Nkosiyazi Dube

APPENDIX B

CONSENT FORM FOR PARTICIPATION IN THE STUDY

I hereby consent to participate in the research project. The purpose and procedures of the study have been explained to me. I understand that my participation is voluntary and that I may refuse to answer any particular items or withdraw from the study at any time without any negative consequences. I understand that my responses will be kept confidential.

Name of Participant: ……………………………………….

Date: ………………………………………………………..

Signature: ……………………………………………………

APPENDIX C

CONSENT FORM FOR AUDIO-TAPING OF THE INTERVIEW

I hereby consent to tape-recording of the interview. I understand that my confidentiality will

be maintained at all times and that the tapes will be destroyed two years after any publication

arising from the study or six years after completion of the study if there are no publications.

Name: ……………………………………….

Date: ………………………………………

Signature: ………………………………….

APPENDIX D

INTERVIEW SCHEDULE FOR THE PERCEIVED EFFECTS OF HIV STATUS DISCLOSURE AND NON-DISCLOSURE TO CHILDREN BORN HIV POSITIVE LIVING AT EPWORTH CHILD AND YOUTH CARE CENTRE IN EKURHULENI

<u>**Demographic data**</u>

Gender: Male

   Female

<u>**Questions**</u>

1. Do you regularly interact with HIV positive children?
…………………………………………………………………………………………………
……………………………………………………………………………………………

2. What is your general understanding about HIV/AIDS?
…………………………………………………………………………………………………
……………………………………………………………………………………………

3. What is your opinion regarding children born HIV positive and why?
…………………………………………………………………………………………………
……………………………………………………………………………………………

4. Do children at Epworth know their HIV status?
…………………………………………………………………………………………………
………………………………………………………………………………………….....

5. What do you think could be the effects of disclosure?
…………………………………………………………………………………………………
…………………………………………………………………………………………….....

6. What about the effects of non-disclosure to them?
…………………………………………………………………………………………………
……………………………………………………………………………………………

7. Have you attempted to disclose and what were your experiences?
…………………………………………………………………………………………………
……………………………………………………………………………………………

8. As a social service professional, what do you think your role is concerning disclosure and non-disclosure to children born HIV positive living at Epworth?

………
………
……

9. What are your recommendations concerning disclosure and non-disclosure of the HIV status to children born HIV positive living at Epworth?
………
……

10. Do you have any questions regarding the study?
………
……

Thank you for your participation.